# HIV/AIDS Risk Factor Reporting Alarmingly Low

Of the approximately 33,000 new HIV/AIDS diagnoses reported to the National HIV/AIDS Reporting System in 2003, over one-third were reported with no identified risk factor, according to a new report by the Centers for Disease Control and Prevention (CDC).

Without accurate risk factor documentation and reporting (which are part of routine case reporting), state and federal funding for HIV prevention activities and AIDS services may not reach the populations who are most in need. Additionally, surveillance tracking of the HIV/AIDS epidemic requires accurate risk factor information to detect changes in the epidemic. According to CDC, the problem is already severe, but there are signs it is getting worse.

"The percent of cases reported without risk factors has been increasing annually," says Kathleen McDavid, PhD, MPH, an epidemiologist with CDC's HIV Incidence and Case Surveillance Branch. "From 1994 to 2003, the percent of HIV cases reported to the CDC without risk factor information has doubled to 40% and the percent of AIDS cases reported without risk factors went from 15% to 27%. Further, some of the cases among groups who are less likely to be reported with risk factors are some of the groups who may need services the most, including African Americans."

## Why is reporting risk factors important?

Risk factor reporting is the beginning of a process that culminates with CDC's surveillance information on HIV and AIDS.

"Once the individual risk factors are collected, they are sent, without patient identifiers, through the state surveillance department to CDC. At the state level and the federal level they are assigned the most probable mode of transmission," says Dr. McDavid. "Even though an individual can have multiple risk factors for HIV infection, he or she will be classified into only one transmission category. It is this category that is the most likely mode of transmission for a particular person."

The risk factor reporting form that healthcare providers use may look very different than the transmission categories reported by CDC. For example, the risk factor questions aim to cover all possibilities. It is not enough to know that a woman newly diagnosed with HIV has had multiple male sex partners. CDC needs to know if one or more of these sex partners was a bisexual male, used injection drugs, may already have been documented with HIV infection, or was otherwise at high risk for HIV. The many facets of information compiled by healthcare professionals are boiled down into the most probable transmission category, that is, the most likely way the patient may have been exposed to HIV.

So even though transmission categories appear in CDC surveillance reports, it is the risk factors that are the seminal pieces of information. Transmission categories are used for various purposes, including:

- Allocating resources. Federal and state governments, non-profit organizations, and private foundations distribute hundreds of millions of dollars each year based on the distribution of transmission categories among cases of HIV infection.
- Monitoring trends. Risk factor data are integral in monitoring trends in the transmission of HIV, as seen in CDC's annual surveillance reports. Trends change over time, making it important to accurately track them. For example, in the early years of the epidemic, most women who received a diagnosis of HIV and AIDS were infected through injection drug use. According to recent surveillance reports, currently, more women are infected through heterosexual contact than through injection drug use.
- Planning prevention programs. Knowing which risk factor groups are most affected in different populations is critical to all of the programs, prevention efforts, and activities undertaken by the many organizations concerned with HIV and AIDS. If this information is not correctly and completely collected, organizations will not accurately distribute resources or create programs to prevent the spread of HIV.
- Targeting risk-reduction interventions. When CDC and other organizations plan risk-reduction interventions or prevention programs, it is vital to know which risk factors are currently driving the epidemic.
- Evaluating various HIV/AIDS programs. Again, accurate risk factor reporting will allow CDC and other organizations to evaluate the effects, e.g., decreasing the

## CDC HIV Transmission Categories

- Men who have Sex with Men (MSM)
- Injection Drug Use (IDU), which includes injecting illicit or non-prescribed drugs
- MSM + IDU, which includes men who have sex with men and also inject drugs
- Hemophilia/coagulation disorder
- Heterosexual contact with a high-risk or infected individual
- Blood, blood component, or transplant recipient
- Other not reported/identified

# HIV/AIDS Risk Factor Reporting Alarmingly Low (continued)

number of new infections or increasing access to care, their programs are having on various risk factor groups.
- Identifying new or unusual cases of HIV infection. Accurate risk factor reporting can signal the emergence of new at-risk groups.

## What are the reasons that risk factors are not reported?

"There are many reasons why risk factors don't get reported, ranging from not having enough time with patients to confidentiality concerns," says Dr. McDavid. Other reasons include:

- Fatigue in case reporting.
- An increase in the turnover of surveillance or provider staff.
- Reduced resources in both health departments and provider settings.
- Inadequate training and retraining of health department staff and providers who take sex and drug risk factor histories from patients and clients.
- Lack of comfort in asking about sexual behavior or drug use.
- The lack of standardized terminology at each step of the process to describe potential routes of exposure and the most likely route of exposure.
- Transition of the source of reports from hospitals to laboratories, outpatient settings, and other places where documentation is less extensive.
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## What is CDC doing?

To better serve its healthcare partners across the country, in January 2004, CDC and state surveillance staffs formed a workgroup to address the concerns. The workgroup revised the surveillance guidelines, including the training guidance, and developed educational materials for providers. These materials, which are expected to be available in 2005, will provide definitions of risk factors, self-assessment tools, and suggestions for discussing risk factors with patients.

Additionally, the surveillance data are some of the most securely collected in the United States. States and CDC adhere to strong national data security and confidentiality guidelines which are reviewed and updated annually.

## What can you do?

"Healthcare providers are in a unique situation," notes Dr. McDavid. "They are on the frontline of HIV and AIDS patient care and are our best opportunity to get this risk factor information. They may also be on the receiving end of funds directed to HIV and AIDS services. Therefore, they may receive the benefits of accurate reporting through monies and services targeted to the populations who need them the most."

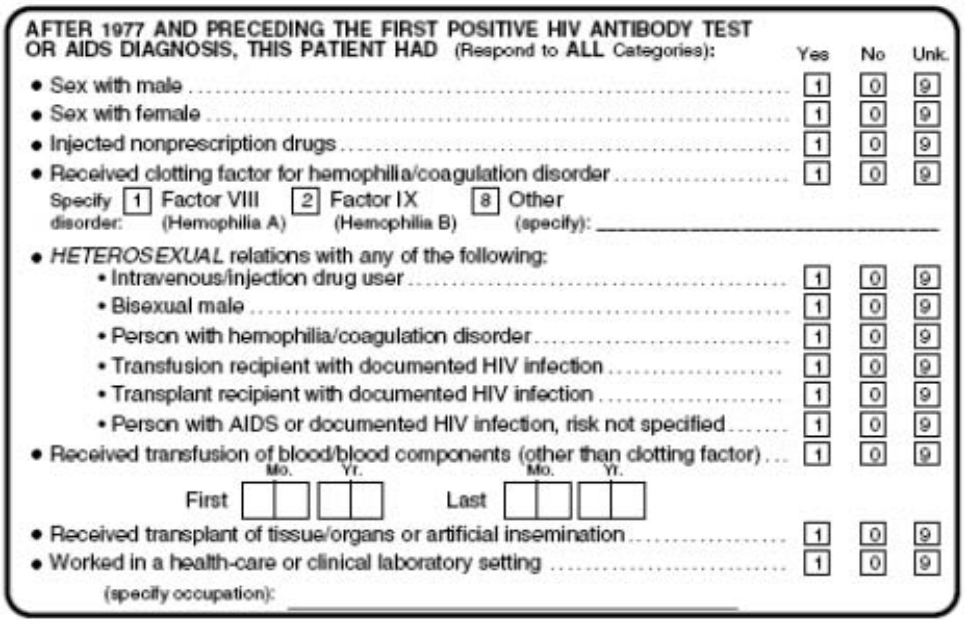
As a healthcare provider, you can

- work with your state and local health departments to ensure that you are completely and accurately assessing patient risk factors and filling out forms.
- request materials and tools from your local health department to assist you to better document all known risk factors.
- make sure your colleagues are properly trained in assessing and documenting all known HIV risk factors according to national and local definitions.

If you don't report risk factor information, you can work with your local health department who can confidentially obtain the information from patient records.

"However you choose to help increase the documenting and reporting of risk factors, your efforts are appreciated and important," says Dr. McDavid. "They will pay off in more accurate surveillance information, better targeting of lifesaving prevention programs, and the assurance that resources are going to the populations who need them most."

**Risk Factor Reporting Section of CDC Case Report Form**



V. PATIENT HISTORY

AFTER 1977 AND PRECEDING THE FIRST POSITIVE HIV ANTIBODY TEST OR AIDS DIAGNOSIS, THIS PATIENT HAD (Respond to ALL Categories):

| | Yes | No | Unk. |
|---|---|---|---|
| • Sex with male | 1 | 0 | 9 |
| • Sex with female | 1 | 0 | 9 |
| • Injected nonprescription drugs | 1 | 0 | 9 |
| • Received clotting factor for hemophilia/coagulation disorder | 1 | 0 | 9 |
| Specify disorder: 1 Factor VIII (Hemophilia A) 2 Factor IX (Hemophilia B) 8 Other (specify): _____ | | | |
| • *HETEROSEXUAL* relations with any of the following: | | | |
| • Intravenous/injection drug user | 1 | 0 | 9 |
| • Bisexual male | 1 | 0 | 9 |
| • Person with hemophilia/coagulation disorder | 1 | 0 | 9 |
| • Transfusion recipient with documented HIV infection | 1 | 0 | 9 |
| • Transplant recipient with documented HIV infection | 1 | 0 | 9 |
| • Person with AIDS or documented HIV infection, risk not specified | 1 | 0 | 9 |
| • Received transfusion of blood/blood components (other than clotting factor) | 1 | 0 | 9 |
| First Mo. Yr. Last Mo. Yr. | | | |
| • Received transplant of tissue/organs or artificial insemination | 1 | 0 | 9 |
| • Worked in a health-care or clinical laboratory setting | 1 | 0 | 9 |
| (specify occupation): _____ | | | |

For further information, please contact your state health department or Dr. McDavid at kmcdavid@cdc.gov.